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Title Page

Running Head: PERCEIVED IMPACT OF COVID-19 IN SPINAL CORD INJURY

Perceived impact of the COVID-19 pandemic among people with spinal cord injury: A descriptive study

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ABSTRACT

Objective: To describe the self-reported impact of the COVID-19 pandemic on the lives of persons with spinal cord injury (SCI).

Design: Cross sectional study.

Participants: There were a total of 382 adult participants with traumatic SCI of at least one-year duration, all of whom were identified through a state-based surveillance registry in the Southeastern United States. The majority of participants were male (68.4%) and 72% were ambulatory. The average age at the time of the study was 57.7.

Main Outcome Measures: Participants completed a self-report assessment (SRA) online or by mail on the impact of COVID-19 on quality-of-life, ability to get daily necessities, and access to healthcare.

Results: Over half of the participants (58.9%) reported a negative impact of the pandemic in at least one of five life areas, with community participation being the primary area affected (51.4%). A small portion of individuals had trouble obtaining necessities, with approximately 12% reporting difficulties getting enough or quality food and 8.2% reporting difficulty getting prescription medications. However, 25% reported delaying healthcare procedures because of fear of catching COVID-19. Among those requiring personal assistance, 32% reported a decrease in quality of care and 51.9% relied more on family to assist with their care.

Conclusion(s): The COVID-19 pandemic had multiple negative impacts. Of particular importance were reduced access to healthcare and declines in quality and stability of attendant care, with greater reliance on family. Fear of contracting COVID-19 when accessing routine medical procedures needs to be addressed in future outbreaks.

Keywords: spinal cord injury; COVID-19; quality-of-life; vaccinations; community participation

List of Abbreviations

PPE	Personal protective equipment
SRA	Self-report assessment
SCI	Spinal cord injury

The COVID-19 pandemic is a public health crisis that has dramatically changed everyday life. COVID-19 has presented challenges to community participation, quality-of-life, and health, as it has restricted community participation and access to daily necessities and services. The pandemic may have particularly adverse effects for those with chronic conditions,¹ including people with severe physical disability, because of both the increased susceptibility to COVID-19 and the disruption in the social, healthcare, and supportive network.² Numerous reports have documented a drop or delay in people seeking healthcare services due to fear of COVID-19, and in some cases, this disruption in care has caused inadvertent harm.³ Changes in behaviors during the lockdown have been well-established,^{4,5} with one study finding that 21% of participants worsened their patterns of behavioral change (increases in smoking, alcohol consumption, and weight and decreases in physical activity levels and sleep), while 25% improved their patterns of behavior (increases in activity levels, decreases in weight and alcohol consumption).⁶

Traumatic spinal cord injury (SCI) typically results in severe physical disability and has a lifelong impact on health, including the development of many secondary or chronic health conditions, such as cardiovascular disease.⁷ Therefore, people with SCI may be at a greater risk for adverse effects from the COVID-19 virus, and have additional difficulties obtaining daily necessities because of limitations in ability to complete tasks in the community. Further, many individuals with SCI depend on personal care attendants to help with daily tasks and long-term care activities. For these people, there is an added element of certain COVID-19 precautions, such as strict isolation and social distancing, not being feasible.

Additional questions can be raised about how the COVID-19 pandemic may have a particularly significant impact on those with more severe SCI, as they require specialized equipment, such as wheelchairs and braces.⁸ These may be more difficult to obtain or service during the pandemic. Of greater importance, personal care assistance has been less available during the pandemic, with fewer workers and work shortages at present.⁹

We are more than three years removed from the onset of the pandemic, yet there is minimal research on the impact of the pandemic on persons with SCI. Clinical studies have indicated that among those with SCI who have had COVID-19, fewer symptoms were exhibited compared to those in the general population, but there was greater clinical severity and often delayed diagnoses and treatments.^{10,11} A study by Monden and colleagues assessed SCI participants' concerns about medical rationing, access to supplies, and impact on overall health and mental health, and found that the pandemic negatively impacted mental health and caused increased difficulty accessing medical supplies.¹² While a few studies have been published, particularly absent are studies that document the perceptions and experiences of people with SCI, as well as studies of actual changes in outcomes.

The purpose of the current study was to describe the perceived impact of the COVID-19 pandemic on the lives of people with SCI. The areas of focus include general adverse impact, ability to obtain daily necessities, and the ability to obtain and maintain SCI supplies, special equipment, and attendant care. Having such information is essential for both understanding the impact of the pandemic from the perspectives of people with SCI, as well as preparing for future outbreaks.

Methods

Participants

Institutional review board was approved prior to initiating data collection. Documentation of informed consent was waived, and the completion and return of the survey indicated the participants' understanding and willingness to participate in this research study. Participants were initially identified through a single state-based, population registry and enrolled in a longitudinal study on health outcomes. The eligibility criteria at enrollment were: 1) minimum of 18 years of age, 2) traumatic SCI, and 3) minimum of one-year post-injury at enrollment. A total of 382 of a possible 590 eligible individuals from the longitudinal outcomes study completed materials during 2020 and 2021, including a supplemental set of questions regarding the perceived impact of the pandemic on multiple areas of life, including basic needs and SCI specialty needs.

Procedures

Prospective participants were sent a letter via mail describing the study and soliciting participation. The letter contained a unique identifier and a link to a web application, REDCap,

so that participants could complete the self-report assessment (SRA) online. If it was not completed within approximately 3-4 weeks, a paper form of the SRA was mailed. Data were recorded by phone for those who had difficulty completing the materials themselves. Two follow-up mailings were utilized and a follow-up phone call. Participants were paid \$40 remuneration to complete the materials. All responses were received between December 2020 to March 2022.

Measures

A short questionnaire regarding COVID-19 was developed in response to the pandemic and added to an existing SRA. It requests mostly objective information on the effects of the pandemic and was designed in the absence of validated measures. Information elicited was used to describe the demographic and injury profiles of the participant. The COVID-19 pandemic questions and the outcome measures in the current report were broken into several sections.

Access to daily living requirements was measured by four yes/no questions, whether they had difficulty obtaining 1) enough food or good quality food, 2) prescription medication(s), 3) transportation, and 4) routine medical or dental care. *Perceived adverse impact of the pandemic on life* was measured by five Likert scales, ranging from strongly disagree to strongly agree, including: 1) social/family/community participation, 2) employment, 3) physical health, 4) mental health, and 5) financial well-being. Several questions asked about general *access to healthcare*, including access to SCI supplies, equipment, and personal care attendants.

Participants also were asked whether they had postponed routine healthcare or treatments. Lastly, status on *testing and vaccination* were ascertained, but only used for descriptive purposes.

Statistical Analysis

All analyses were completed using IBM SPSS Statistics for Windows, version 25.^a Basic descriptive statistics were used to describe the study participants in outcomes. Simple frequency counts were used to describe the responses. Means and standard deviations were calculated.

Results

Description of the Study Cohort

Most participants were non-Hispanic white (56.8%), followed by non-Hispanic black (36.2%; table 1). Sixty-eight percent were male. The average age of participants was 57.7 and the average years of education was 12.9. In terms of SCI characteristics, 70.5% percent reported cervical injuries, 19.9% thoracic, 8.9% lumbar, and .6 sacral. Seventy two percent were ambulatory. The average number of years since SCI onset was 13.1.

At the time of the study, 45.8% had been tested for COVID-19 and 13.5% of those tested positive (table 2). Just over 10% reported also having a family member who had tested positive. At the time of participation, 60.6% reported that the vaccine was available. Of these, 41.7% had received the vaccine. Of those who had not been vaccinated, 55.3% reported they planned to get vaccinated. Of those not planning to be vaccinated, the vast majority reported concerns with side effects (69.4%), 12% reported transportation difficulties, and 4.6% reported cost.

Daily requirements

A small percentage reported difficulties getting prescription medications (8.2%; figure 1), getting enough or good quality foods (12.1%), or having difficulty with transportation, getting to and from places (12.4%; table 2). A higher percentage (15.5%) reported difficulty getting routine medical or dental care, and 25% reported delaying or canceling a medical procedure, treatment,

or therapy, due to fear of catching COVID-19. However, only 8.8% reported difficulty getting timely treatment for SCI problems, such as urinary tract infections or pressure ulcers.

Perceived impact on life outcomes

The majority (58.9%; figure 2) of participants agreed or strongly agreed that COVID-19 affected at least one area of their life. Thus, 41.1% strongly disagreed, disagreed, or were neutral to statements regarding the impact of COVID-19 on quality-of-life. More than half of the participants (51.4%) reported that COVID-19 restrictions negatively affected their community participation (table 2). A smaller, yet significant, percentage indicated concerns with other areas that included mental health (28.8%), financial well-being (26.6%), physical health (22.7%), and employment (20.7%).

SCI-specific needs

Because the majority were ambulatory, only 39.5% reported needing special SCI equipment; 34.7% reported use of regular SCI supplies, such as catheters or gloves. While 21.3% of those requiring special equipment had difficulties with maintenance, 35.5% reported more difficulty maintaining their regular SCI supplies. Just under 15% required the use of personal care assistance. Of this group, 32.1% indicated that the quality of their personal care declined since the pandemic, 37% reported an attendant leaving or reducing their hours, and over half (51.9%) reported having to rely on family members for care more than usual (figure 3).

Discussion

This study addresses a significant gap in literature as it describes the *perceived impact* of the COVID-19 pandemic on ability to obtain daily necessities, access to care, and adverse impact on

key areas of life. Some questions addressed special needs of those with more severe SCI related to ability to get and maintain equipment, supplies, and appropriate attendant care. These findings help us better understand the scope of the problem with the pandemic and SCI and to help to plan for potential adverse outcomes of future outbreaks. Although we also asked about vaccination and testing for the disease, we could only report general findings as these indicators were often queried early in the pandemic, often prior to the availability of vaccine.

Several important findings emerged from the data. First, there were a limited portion of individuals who reported difficulties obtaining daily necessities, such as food, transportation, or prescription medication (these ranged between only 8.2% and 15.5%). It was somewhat surprising that, other than reduced community participation where just over half of the participants (51.4%) reported adverse effects of the pandemic, there were relatively small portions of individuals who indicated adverse effects in other areas, especially considering that this is a representative sample of the SCI population, rather than simply those with SCI who were treated by specialty hospitals. There are several potential explanations why the perceived adverse effects of the pandemic were not more severe. First, those with SCI already have ongoing challenges to their social participation and quality-of-life. In terms of daily necessities, many people already have an established support system for maintaining daily necessities, so perhaps a portion of the participants were already doing those things necessary to survive during the pandemic.

There were significant concerns with people who have reported delaying or canceling a medical procedure, treatment, or therapy, due to fear of catching COVID-19 (25.1%). In the United States general population, an even higher percentage (40.9%) of adults avoided medical care during the pandemic.¹³ However, this is likely explained by the fact that those with SCI are more

plugged into the healthcare system over the general population, with one study finding that those with SCI have an average of 22 contact points in the healthcare system in the year of injury compared to 3 within the general population.¹⁴ Given the profound impact of SCI on health and likelihood of developing secondary health conditions,¹⁵ it is disconcerting that people were choosing not to get therapies and treatments. The potential impact of people not receiving needed treatment may be particularly poignant for those therapies that are needed to preserve function and independence, and to treat and prevent life-changing and life-threatening secondary health conditions, such as pressure ulcers. Pressure ulcers and UTIs are associated with a much greater likelihood of mortality.¹⁶⁻¹⁸ Therefore, even though a smaller portion of people with SCI delayed needed procedures when compared with the general population, it is highly likely that those procedures were related to more severe conditions and may have more impact by virtue of the delays. This however is an empirical question, and we cannot answer it definitively based on the current data.

There was a significant issue with attendant care, as 32.1% of the participants with paid attendant care indicated that the quality of their care had diminished. Moreover, nearly 52% indicated greater reliance on family members for their care. This is of concern because quality attendant care is essential to maximizing independence, which is a fundamental goal of rehabilitation, and to ensure individuals live in the least restrictive environments, as mandated by the Olmstead act.¹⁹ Additional reliance on family members brings in individuals closer to yet even more restricted environments, such as assisted living and nursing home placements. In addition to personal risk of COVID-19, of concern is that 10.2% of the participants had someone in their household with COVID-19. Wages for caregivers are typically low and often without benefits. The elevated levels of job-related physical and emotional stress during the pandemic^{20,21} may be

adding to difficulties maintaining the support necessary to live independently. This was supported by our finding that 37% of participants lost caregivers or had reduce caregiver hours since the beginning of the pandemic. Additionally, health care providers, including personal care attendants, are at a heightened risk for developing and spreading COVID-19, as they cannot social distance.²² Our findings underscore the fragility of the personal care attendant system, which was already facing challenges and high turnover prior to the pandemic.²³ Policy changes are needed to improve prestige, wages, and benefits of those doing home care.

Given the difficulties reported in obtaining regular supplies, there had been critical shortages of personal protective equipment (PPE),²⁴ which no doubt has led to difficulties obtaining PPE for both those with SCI and their personal care attendants. PPE is essential for catheter and bowel programs. Our findings revealed that, among those needing regular SCI supplies, 41.4% reported more difficulty obtaining them. The challenge to obtain these supplies is of concern, since hand hygiene, especially the use of latex gloves, can prevent infections.^{25,26} One study revealed that during COVID, having access to adequate PPE increased feelings of safety and led to better job gratification and less distress among healthcare workers.²⁷

Study Limitations

There are several important strengths of the current study. First, the timing of the data collection, with a group of longitudinal participants, provided insights into the consequences of the pandemic, including needs for supplies, equipment, and personal care assistance. A second strength was identifying participants through a state SCI registry, which is population-based. Use of this cohort of participants reduced selection bias and has greater generalizability than studies of completely self-selected volunteers identified through advertisements, or recruitment through specialty hospitals where admission practices may exclude lower socioeconomic participants.

There are several limitations. First, the instrument requested only basic information and was not validated against objective indicators. It therefore does not allow for comparisons with the general population. Such comparisons were beyond our goal, which was simply to probe how the COVID-19 pandemic was impacting the lives of people with SCI. Second, all data were self-report and susceptible to reporting biases. We specifically measured perceived impact, so actual impact may differ in unknown ways. Third, because of the sudden and unexpected nature of the pandemic, we had no option to fully align items with other efforts nationally, so we cannot directly compare our observed outcomes directly with other studies. Fourth, our sample size is relatively small for specific subgroups, such as those who require personal care assistance or those requiring specialized equipment and supplies. Therefore, we have only limited information on these individuals. Fifth, the data are cross-sectional, assessed on a single occasion, even though part of a larger longitudinal study. The data were collected from a single region – a state within the southeastern United States, and there are regional factors that affect vaccine distribution. Additionally, because we implemented the study as early as possible after the onset of the pandemic, the severity of the impact of COVID-19 shifted between the study's inception and the study's conclusion. Lastly, although we collected data on history of disease and vaccination, the vaccine was not yet available when some participants responded. So, the data can only be used for rough descriptive purposes and not for epidemiologic estimates.

Future Research

Longitudinal studies are needed that have both pre-and post- COVID-19 assessments, rather than the single cross-sectional self-report assessment, to identify actual changes in outcomes over the COVID-19 pandemic, rather than perceptions of changes in outcomes. There is a need to incorporate COVID-19 and related items within larger ongoing data collection efforts, such as

the SCI Model Systems in the USA. This would help us monitor the impact of the pandemic over time, including future outbreaks. We also need to identify how long it takes for outcomes to recover after the original pandemic subsides and any lingering effects that will depend on the ultimate course of COVID-19.

More broadly, we need to identify the effects of COVID-19 among those who have caught the virus. Is the course more deadly for those with SCI than those in the general population? In terms of vaccination, it was noteworthy that a substantial portion of people with no plans to get vaccinated reported concerns of side effects. We also need to better understand the actual complications or side effects from vaccination and whether some of these are exacerbated by SCI, such as increased spasticity or dysreflexia.

Conclusion

Participants have perceived that the COVID-19 pandemic has adversely impacted their lives to varying degrees, although the effects are not universal. A portion of individuals have experienced difficulties meeting daily needs and over one quarter of the participants reported delaying or canceling medical procedures or therapies.

Suppliers

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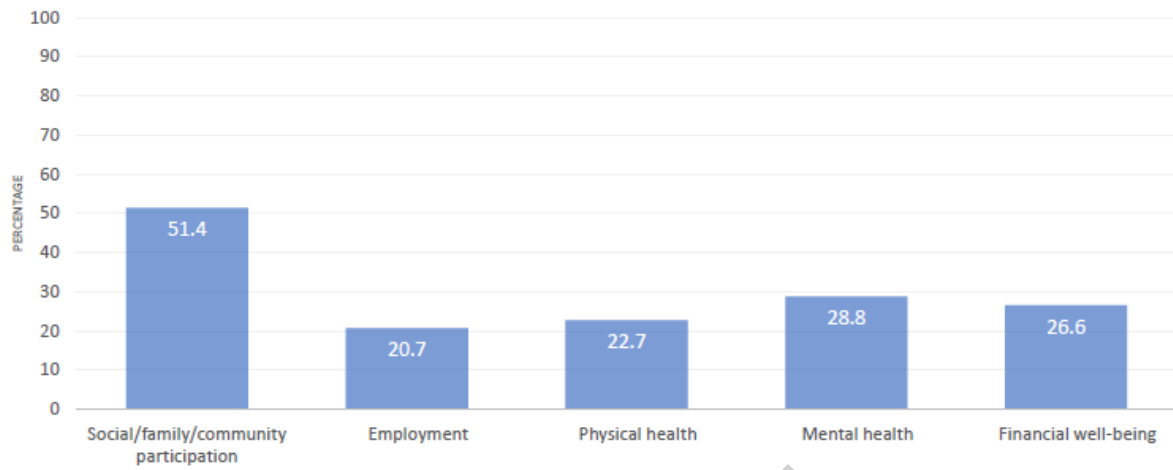


Figure 1. Self-reported difficulties in obtaining daily necessities and needed treatments due to COVID-19

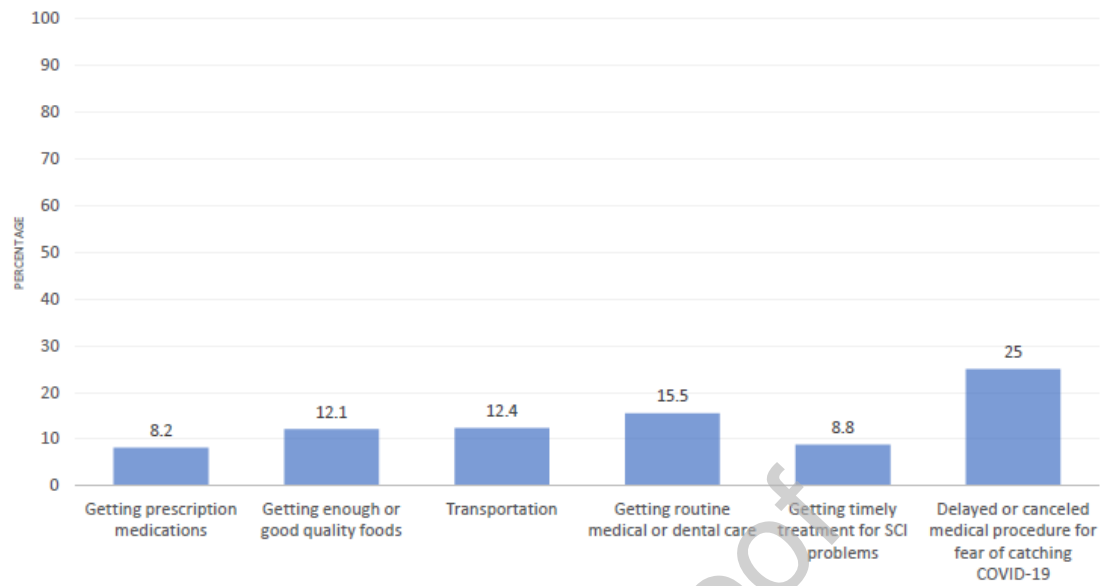
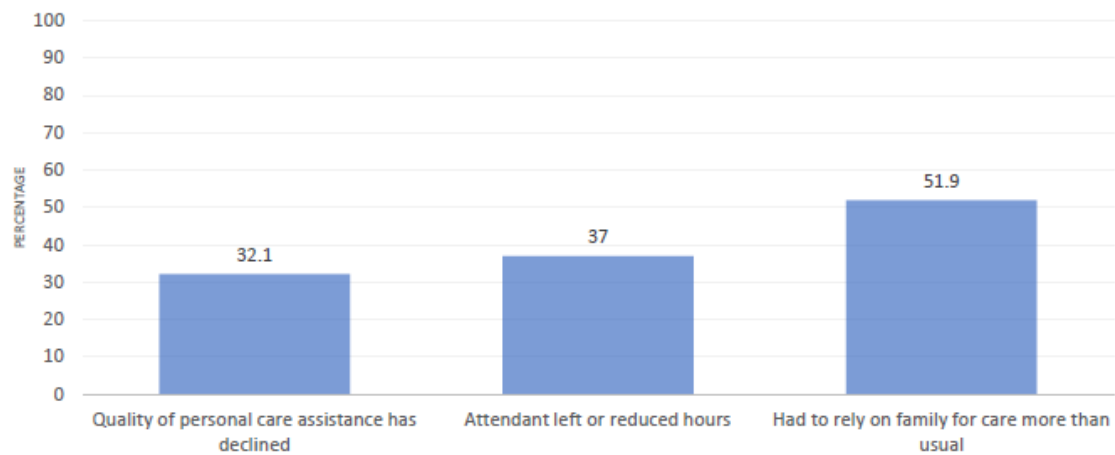


Figure 2. Percentage of participants agreeing or strongly agreeing that they were adversely affected by COVID-19 in each of five areas



Note: 15% of the participants required attendant care

Figure 3. Changes in access and quality of personal care assistance for individuals with SCI who required daily assistance to meet their needs

Table 1. Description of demographic variables

Variables	N (%)
Sex	
Male	245 (68.4%)
Female	113 (31.6%)
Race/Ethnicity	
Non-Hispanic White	210 (56.8%)
Non-Hispanic Black	134 (36.2%)
Hispanic	11 (3.0%)
Other	15 (3.9%)
Injury Severity	
Cervical	237 (70.5%)
Thoracic	67 (19.9%)
Lumbar	30 (8.9%)
Sacral	2 (0.6%)
Ambulatory	273 (72.0%)
Relationship Status	
Married or unmarried couple	167 (44.3%)
Divorced, widowed, separated, never married	210 (55.7%)
Mean (SD)	
Age	57.7 (15.3)
Time Since Injury	13.1 (9.0)
Years of Education	12.9 (3.2)

Table 2. Self-reported effects of COVID-19 pandemic restrictions

Variables	Yes (%)
Tested for COVID-19	45.8
Tested positive for COVID-19	13.5
Family member tested positive for COVID-19	10.2
Vaccine available	60.6
If yes, been vaccinated	47.1
If no, plan to be vaccinated	55.3
Of those not planning to be vaccinated, reasons include	
Concerned about side effects	69.4
Concerned about transportation difficulties	12.0
Concerned about cost	4.6
COVID-19 affected:	
Social/family/community participation	51.4
Employment	20.7
Physical health	22.7
Mental health	28.8
Financial well-being	26.6
Difficulty getting prescription medications	8.2
Difficulty getting enough or good quality foods	12.1
Difficulty with transportation	12.4
Difficulty getting routine medical or dental care	15.5

Difficulty getting timely treatment for SCI problems	8.8
Delayed or canceled medical procedure for fear of catching COVID-19	25.0
Needed special SCI equipment	39.5
Of those, difficulty maintaining SCI equipment	21.3
Needed SCI supplies	34.7
Of those, difficulty maintaining SCI supplies	35.5
Needed personal care assistance	14.7
If yes, quality has declined	32.1
If yes, attendant left or reduced hours	37.0
If yes, had to rely on family for care more than usual	51.9